

J R C T E C H N I C A L R E P O R T S

European Commission **Initiative**
on **Breast Cancer**–ECIBC:

**Organisation of project guiding
and support meetings report–2015**

Luciana Neamțiu, Anke Bramesfeld,
Silvia Deandrea, Donata Lerda,
Jesús López Alcalde, Liisa Pylkkanen,
Zuleika Saz-Parkinson, Aslı Ulutürk

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Contact information

Name: Donata Lerda

Address: Joint Research Centre, IHCP, Public Health Policy Support, Via Enrico Fermi 2749, TP 127, 21027 Ispra (VA), Italy

E-mail: jrc-cancer-policy-support@ec.europa.eu

Tel.: +39 0332 78 6201

Fax: +39 0332 78 9059

Web: <http://ecibc.jrc.ec.europa.eu>

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ABSTRACT

In December 2012, the Joint Research Centre (JRC), which is the European Commission's (EC) in-house science service, was assigned by the Directorate-General for Health and Consumers (now the Directorate-General for Health and Food Safety–DG SANTE) with the task of coordinating the European Commission Initiative on Breast Cancer (ECIBC). Further details can be retrieved in the following sources:

- [European Commission Initiative on Breast Cancer: Concept document.](#)
- [JRC webpage: European Commission Initiative on Breast Cancer–ECIBC.](#)

The JRC set up a dedicated team for coordinating the ECIBC; the Healthcare Quality team (HQ). ECIBC main tasks as defined by the DG SANTE document are:

1. To develop a new version of the European guidelines for breast cancer screening and diagnosis based on new knowledge and evidence;
2. To develop a voluntary European quality assurance (QA) scheme for breast cancer services based on the EU legislative framework on accreditation, as defined in the Regulation of the European Parliament and by the Council of Europe setting out the requirements for accreditation and market surveillance.

With regard to guidelines covering stages other than screening and diagnosis, a platform for breast cancer guidelines is envisaged to host existing evidence-based, high-quality guidelines.

Other tasks, such as the development of the ECIBC web hub and the definition of a concept for training of professionals in breast cancer screening, were included. Moreover, tasks functional to the creation of the necessary knowledge platform were also assigned and new tasks will be added, as needed.

In order to develop the ECIBC project in a coordinated, consensus-based and sustainable way, the JRC set up a series of targeted meetings with a wide range of stakeholders involved in similar initiatives (past and current), including medical oncology professionals, accreditation bodies, patient organisations, methodologists, experts and concerned national authorities. The JRC also participated in external meetings and conferences in order to acquire the basic knowledge for starting the activities of the ECIBC and to inform stakeholders about the ECIBC's aim and tasks.

The present report is a summary of the 2015 meetings aimed at helping the preparation of the above mentioned tasks. The meetings organised between 2011 and 2014 are described in the JRC reports *European Commission Initiative on Breast Cancer–ECIBC: organisation of project guiding and support meetings–Meetings 2011-2013* and, respectively, *European Commission Initiative on Breast Cancer–ECIBC: organisation of project guiding and support meetings–Meetings 2014*.

1. Introduction

The ECIBC is coordinated by the JRC's Institute for Health and Consumer Protection (JRC-IHCP). This initiative responds to the *Council Conclusions on reducing the burden of cancer*¹ and it aims to mitigate the risks associated with inadequate quality of prevention and care. In this context, the tasks of the initiative can be summarised as (i) establishing a minimum set of evidence-based quality requirements for breast cancer care across Europe assessed and monitored via the accreditation legal framework (a voluntary European quality assurance scheme for breast cancer services) while (ii) developing the evidence underpinning the scheme, namely the new *European guidelines for breast cancer screening and diagnosis* (hereinafter mentioned as new *European Guidelines*) and a platform for existing guidelines for other stages of care. Its concept foresees that all aspects of breast cancer prevention and care, screening, diagnosis, treatment, survivorship–support–palliative care and management of recurrence (follow-up) are covered.

In addition, the initiative will: (iii) develop a concept for training health professionals involved in digital mammography screening programmes; and (iv) develop a concept for the ECIBC web hub which should act as a host for all its deliverables in order to make them easily accessible to target users.

These four tasks are strongly interlinked and their accomplishment will rely on inputs from relevant European and international stakeholders, experts and participating countries (Member States–MSs, plus Switzerland, Iceland, Montenegro, Norway, Serbia, Turkey). Therefore, a series of meetings targeting the widest possible audience of interested parties began in 2012. As these meetings were an important source of information and a platform for consensus for future stages of the project, the JRC will continue to invest ECIBC resources to disseminate the information related to the project and to identify and meet with stakeholders.

1. Council of the European Union. *Council Conclusions on reducing the burden of cancer*. 2876th Employment, Social Policy, Health and Consumer Affairs Council Meeting. Luxembourg, 10 June 2008.

2 . Scope

This report includes a description of the context and outcomes of the meetings held in 2015, the news about the ECIBC and the relevant stakeholders the JRC met during 2015. JRC staff involved in the meetings included the IHCP Director, the Head of Unit for Public Health Policy Support (PHPS) and PHPS staff, in particular the Healthcare Quality (HQ) team. Only meetings and events which target the ECIBC are included in the present report.

Meetings involving the JRC and the main customer, DG SANTE, the Expert Group on Cancer Control or other concerned DGs and EU bodies, like Directorate-General for Research and Innovation (DG RTD), Directorate-General for Enterprise and Industry (DG GROW) are cited but not fully described as they do not fall under the scope of this report. Also for the big events organised by JRC in the framework of the ECIBC separate reports are prepared.

3

. Methods

The methods used for identifying relevant stakeholders have already been described in the report *European Commission Initiative on Breast Cancer–ECIBC: organisation of project guiding and support meetings–Meetings 2011-2013*.

The same structure of the interactions with the stakeholders as in the previous meetings reports was kept:

- attendance at conferences/workshops/trainings as participants,
- attendance at conferences/workshops/trainings as presenters,
- meetings with other EC institutions,
- bilateral meetings with selected external organisations or individual experts,
- attendance at events related to the CAN-CON (European Guide on Quality Improvement in Comprehensive Cancer Control) joint action,
- ECIBC updates, and
- meetings analysis.

4. Results

During 2015, the JRC organised nine bilateral meetings with representatives of various organisations, associations, networks or EU projects. JRC staff (mainly HQ team members) attended 16 external meetings (*e.g.* seminars, conferences, trainings, workshops, working groups) and participated in three meetings within the CANCON joint action framework.

In September 2015, the JRC organised the kick off meetings of the Guidelines Development Group (GDG) and the Quality Assurance Scheme Development Group (QASDG). The GDG will support the European Commission in developing the *European guidelines for breast cancer screening and diagnosis*. The QASDG will support the European Commission in developing the *European Quality Assurance Scheme for breast cancer services*. The members of both groups were selected via a call for expression of interest issued by DG SANTE in 2014 and nominated on 7 July 2015. The first meeting of the GDG was dedicated to the introduction to the ECIBC project, to the working modalities and to the scope of the guidelines. A short training on methods in guidelines development was also provided. The first meeting of the QASDG was dedicated to the introduction to the ECIBC project, to the working modalities and to the scope of the scheme. The full description of both events can be found in the *European Commission Initiative on Breast Cancer: kick-off meetings' report* (in preparation).

Also, the JRC together with the European Association of Research and Technology Organisations (EARTO), the European Committee for Standardization (CEN), the European Committee for Electrotechnical Standardization (CENELEC), and the Directorate-General for Internal Market, Industry, Entrepreneurship and SMEs organised the conference entitled 'Putting Science into Standards: Evidence-based quality assurance—an example for breast cancer'. The scope of this conference was to bring the scientific and standardisation communities closer together with a prime focus on the European Commission Initiative on Breast Cancer (ECIBC). Understanding the processes involved in the ECIBC project, in particular 'healthcare' accreditation, and seeing whether standardisation may play a role in supporting the development and implementation of the European QA scheme, was one of the main objectives of this conference. This event is described in the PSIS report (in preparation).

4.1. List of stakeholders

Table 1 provides the list of European and international organisations/associations, professional societies and patients' associations approached by the JRC since 2011. Stakeholders listed in italics were first approached in 2015.

Table 1. Stakeholders (European and international organisations, professional societies, patients' associations) ordered by acronym.

| No | Name | Activity | Website |
|----|--|---|---|
| 1 | ANEC | <i>ANEC is the European consumer voice in standardisation. They represent the European consumer interest in the creation of technical standards, especially those developed to support the implementation of European laws and public policies.</i> | http://www.anec.eu/anec.asp |
| 2 | Austrian Standards Institute | <i>The Austrian Standards Institute is a non-profit service organization founded in 1920, and its subsidiary Austrian Standards plus GmbH, was established in 2008. Austrian Standards supports the economy, administration, science and consumers in setting standards; organizes and manages committees drafting and developing standards;; publishes national, European and International standards.</i> | https://www.austrian-standards.at/en/home/ |
| 3 | BCN – Breast Centres Network | Breast Centres Network is the first international network of clinical centres exclusively dedicated to the diagnosis and treatment of breast cancer. It is a project of ESO (European School of Oncology) with the aim to promote and improve breast cancer care in Europe and throughout the world. The network includes Breast Units (Multidisciplinary Breast Centres) that fulfil minimum requirements to be considered referral centres. | http://www.breastcentresnetwork.org/ |
| 4 | CEN/CENELEC – European Committee for Standardization | CEN/CENELEC was officially created as an international non-profit association based in Brussels on 30 October 1975. Through its services it provides a platform for the development of European Standards and other technical specifications. CEN is a major provider of European Standards and technical specifications. It is the only recognized European organization according to Directive 98/34/EC for the planning, drafting and adoption of European Standards in all areas of economic activity with the exception of electrotechnology (CENELEC) and telecommunication (ETSI). | http://www.cen.eu/cen/pages/default.aspx |
| 5 | CPME – Comité permanent des médecins Européens | <i>The Standing Committee of European Doctors (CPME) represents national medical associations across Europe.</i> | http://www.cpme.eu/ |
| 6 | DGS – German Society of Senology (Deutsche Gesellschaft für Senologie) | DGS started an accreditation system as a pilot project from the University-Hospital in Tübingen in 2002. The system is now completely implemented all over Germany; more than 93% of primary breast cancer patients are now diagnosed and treated in Certified Breast Cancer Centres. | http://www.senologie.org/ |
| 7 | DKG – German Cancer Society (Die Deutsche Krebsgesellschaft) | The German Cancer Society (DKG) is the largest scientific and professional oncology society in Germany, based in Berlin. Overall, the DKG has approximately 6 600 members. The DKG is a public health institution that works in formal cooperation with politicians, professional societies, service and product providers in healthcare markets, and patient claims for the benefit of cancer patients. It represents the Federal Republic of Germany in international organisations such as the International Union Against Cancer (UICC) and the European Union. The DKG is linked with all European cancer societies and is actively committed to the advancement of a common European health policy. | http://www.krebsgesellschaft.de/ |

Table 1. (cont.)

| No | Name | Activity | Website |
|----|---|--|---|
| 8 | EA – European co-operation for Accreditation | The European co-operation for Accreditation (EA) is an association of national accreditation bodies in Europe that are officially recognised by their national governments to assess and verify – against international standards – organisations that carry out evaluation services such as certification, verification, inspection, testing and calibration (also known as conformity assessment services). | http://www.european-accreditation.org/ |
| 9 | EAPC – European Association of Palliative Care | The EAPC strives to develop and promote palliative care in Europe through information, education and research using multi-professional collaboration, while engaging with stakeholders at all levels. | http://www.eapcnet.eu/ |
| 10 | EAPM – European Alliance for Personalised Medicine | Founded in 2012, EAPM brings together Europe's leading healthcare experts, healthcare organisations and institutions, and patient advocates to improve patient care by accelerating the development, delivery and uptake of personalised healthcare including personalised medicine and diagnostics. EAPM works developing case studies, organising workshops, education, training and communication. | http://euapm.eu/ |
| 11 | EARTO – European Association of research and technology organisations | <i>EARTO is a non-profit association that represents the interests of Europe's Research and Technology Organisations (RTO) community towards European institutions and offers its members opportunities for networking and professional improvement.</i> | http://www.earto.eu/ |
| 12 | ECCC – European Cancer Care Certification | European Cancer Care is an association which has been appointed by Eusoma to develop the voluntary certification process of breast centres. | http://www.cancercarecert.biostatistica.net/index.php |
| 13 | ECCO – European CanCer Organisation | ECCO is a not-for-profit federation that exists to uphold the right of all European cancer patients to the best possible treatment and care, promoting interaction between all organisations involved in cancer at European level. | http://www.ecco-org.eu/ |
| 14 | ECL – Association of European Cancer Leagues | ECL is a pan-European umbrella organisation of national and regional cancer leagues. It provides advocacy for the Members of European Parliament (MEPs) Against Cancer (MACs) and is actively involved in Cancer Joint Actions, the health and nutrition platform, and the National Cancer Control Plans. | http://www.europeancancer-leagues.org/ |
| 15 | ECN – European Cancer Network | ECN has the scope to integrate new Member States and applicant countries into the mainstream of European efforts toward continuous improvement of best practices in secondary cancer prevention. Assistance was provided for the implementation of evidence-based screening tests for breast, cervical and colorectal cancer recommended in the Commission proposal for a Council recommendation on cancer screening which is linked to European Cooperation on Development and Implementation of Cancer Screening and Prevention Guidelines (ECCG). | http://ec.europa.eu/eahc/projects/database.html?prjno=2004309 |

Table 1. (cont.)

| No | Name | Activity | Website |
|----|--|---|---|
| 16 | ECP – European Cancer Prevention Organization | ECP was established in the early 1980s in order to foster action to prevent cancer. | http://ecpo.org/ |
| 17 | ECPC – European Cancer Patient Coalition | Established in 2003, the European Cancer Patient Coalition is the voice of the European cancer patient community, uniquely representing the interests of all cancer patient groups. It was set up: to represent the views of cancer patients in the European healthcare debate; to enable and empower cancer patients by educating them about cancer and advocacy skills and to provide a forum for European cancer patients to exchange information and share concerns on cancer care policies in their countries and best practice experiences. | http://www.ecpc.org/ |
| 18 | EFOMP – European Federation of Organisations in Medical Physics | EFOMP is an umbrella organisation to all national member organisations (NMOs) having as their principal category of members medical physicists in Europe. | http://www.efomp.org/ |
| 19 | EMA – European Medicines Agency | EMA is a decentralised agency of the European Union. The Agency is responsible for the scientific evaluation of medicines developed by pharmaceutical companies for use in the European Union. | http://www.ema.europa.eu |
| 20 | EONS – European Oncology Nursing Society | The European Oncology Nursing Society is a pan-European organisation dedicated to the support and development of cancer nurses. | http://www.cancernurse.eu/ |
| 21 | EORTC – European Organisation for Research and Treatment of Cancer | The aims of EORTC are to develop, conduct, coordinate, and stimulate translational and clinical research in Europe to improve the management of cancer and related problems by increasing survival but also patient quality of life. | http://www.eortc.org/ |
| 22 | ESMO – European Society for Medical Oncology | The European Society for Medical Oncology (ESMO) is a non-profit professional medical oncology society in Europe. ESMO offers post-graduate education and training in clinical cancer care and research, and produces evidence-based recommendations for basic standards of cancer care. | http://www.esmo.org/ |
| 23 | ESO – European School of Oncology | ESO has the aim of contributing to the reduction of deaths from cancer due to late diagnosis and/or inadequate treatment, by improving the skills of all health professionals dealing with cancer patients. | http://www.eso.net/ |
| 24 | ESR – European Society of Radiology | ESR is an apolitical, non-profit organisation, dedicated to promoting and coordinating the scientific, philanthropic, intellectual and professional activities of radiology in all European countries. | http://www.myesr.org/start/ |

Table 1. (cont.)

| No | Name | Activity | Website |
|----|--|---|---|
| 25 | EUPHA – European Public Health Association | EUPHA is an umbrella organisation for public health associations and institutes in Europe. Founded in 1992, EUPHA is an international, multidisciplinary, scientific organisation, bringing together approximately 14 000 public health experts for professional exchange and collaboration throughout Europe. Its mission is to build capacity and knowledge in the field of public health, and to support practice and policy decisions through scientific evidence and producing and sharing knowledge with its members and partners in Europe. EUPHA activity is based on four pillars: Research, Policy, Practice, and Training and Education. In addition, 20 theme-specific sections are active. | http://www.eupha.org/ |
| 26 | EUREF – European Reference Organisation for Quality Assured Breast Screening and Diagnostic Services | EUREF is a pan-European organisation, widely drawn from different MSs and is operated on a non-profit making basis. EUREF commits itself to the development and dissemination of the European Guidelines, certification of breast services and mammography equipment, training and provides support and advice on such issues. | http://www.euref.org/ |
| 27 | Europa Donna – The European Breast Cancer Coalition | Europa Donna is an independent non-profit organisation whose members are affiliated groups from countries throughout Europe. It works to raise awareness of breast cancer and to mobilise the support of European women in pressing for improved breast cancer education, appropriate screening, optimal treatment and increased funding for research. Europa Donna represents the interests of European women regarding breast cancer to local and national authorities as well as to institutions of the European Union. | http://www.europadonna.org/ |
| 28 | Europa Uomo – The European Prostate Cancer Coalition | <i>Europa Uomo is the European advocacy movement for the fight against prostate cancer. Europa Uomo's objective is to increase awareness on prostate cancer in Europe. Europa Uomo is a European coalition of patients supporting groups for prostate diseases in general and prostate cancer in particular.</i> | http://www.europa-uomo.org |
| 29 | EUOPREV – European Network for Prevention and Health Promotion in Family Medicine and General Practice | EUOPREV aims to promote evidence-based disease prevention in general practice/family medicine in Europe. | http://www.euoprev.org/ |
| 30 | EUSOBI – European Society of Breast Imaging | European Society of Breast Imaging (EUSOBI) is a society focused on breast imaging and creating unique medical and scientific standards in the field, it provides various training and fellowship programmes on breast imaging. | http://www.eusobi.org/ |

Table 1. (cont.)

| No | Name | Activity | Website |
|----|--|---|---|
| 31 | EUSOMA – European Society of Breast Cancer Specialists | EUSOMA is a multidisciplinary society committed to improving and harmonizing the standards of breast cancer care in Europe to make sure that all women have access to the best possible specialist breast diagnosis and treatment services. | http://www.eusoma.org/ |
| 32 | Fundación para el Fomento de la Investigación Sanitaria y Biomédica de la Comunidad Valenciana (FISABIO-CSISP) | FISABIO (the Foundation for the Promotion of Health and Biomedical Research of the Valencian Community) is a non-profit scientific and social institution, whose primary purpose is to encourage, promote and develop scientific, technical, health and biomedical research in the Valencian Community (Spain). | http://www.csisp.gva.es/ |
| 33 | G-I-N – Guidelines International Network | G-I-N is a global network that supports evidence-based health care and improved health outcomes by reducing inappropriate variation throughout the world. G-I-N mission is to lead, strengthen and support collaboration and work within the guideline development, adaptation and implementation community. | http://www.g-i-n.net/ |
| 34 | GISMa – Gruppo Italiano Screening Mammografico | GISMA is the Italian multidisciplinary association that promotes the diffusion of population-based breast cancer screening programmes in Italy and monitors the quality of diagnosis and treatment offered in these programmes. | http://www.gisma.it/ |
| 35 | IACR – International Association of Cancer Registries | IACR is a professional society dedicated to fostering the aims and activities of cancer registries worldwide. It is primarily for population-based registries, which collect information on the occurrence and outcome of cancer in defined population groups. | http://www.iacr.com.fr/ |
| 36 | IARC – International Agency for Research on Cancer | IARC is the specialised cancer agency of the World Health Organization. The objective of the IARC is to promote international collaboration in cancer research. | http://www.iarc.fr/ |
| 37 | CClb – Centro Cochrane Iberoamericano | <i>The Iberoamerican Cochrane Centre was formally registered in 1997 as the Spanish Cochrane Centre and is one of the fourteen international centres of Cochrane.</i> | http://es.cochrane.org/es |
| 38 | ICC – Italian Cochrane Centre | ICC is affiliated with the Cochrane Collaboration (CC). The objectives of the ICC are centred on supporting various activities of the Cochrane Collaboration within Italy. | http://www.cochrane.it/ |
| 39 | IPOS – International Psycho-Oncology Society | The International Psycho-Oncology Society (IPOS) was created to foster international multidisciplinary communication about clinical, educational and research issues that relate to psycho-oncology and primary psychosocial dimensions of cancer. | http://www.ipos-society.org/ |
| 40 | JCI – Joint Commission International | JCI works with health care organizations, governments, and international advocates to promote rigorous standards of care in three ways: accreditation, education, and advisory services. | http://www.jointcommissioninternational.org/ |

Table 1. (cont.)

| No | Name | Activity | Website |
|----|--|---|---|
| 41 | NICE – National Institute for Health and Care Excellence | NICE provides national guidance and advice to improve health and social care. It was originally set up in 1999 as the National Institute for Clinical Excellence, a special health authority, to reduce variation in the availability and quality of NHS treatments and care. In 2005, it began developing public health guidance to help prevent ill health and promote healthier lifestyles. In 2013 it took responsibility for developing guidance and quality standards in social care. | https://www.nice.org.uk/ |
| 42 | OECI – Organisation of European Cancer Institutes | The primary objectives of OECI's 68 associated European Cancer Centres are to improve communication and to increase collaborative activities among European cancer institutes. These goals are achieved by promoting and strengthening Comprehensive Cancer Centres in Europe. | http://www.oeci.eu/ |
| 43 | Senonetwork – Associazione Senonetwork Italia Onlus | Senonetwork is the Italian network of breast cancer services. It has the goal of promoting the treatment of breast cancer diseases in Italy in devoted centres which respect the European standards. | http://www.senonetwork.it/ |
| 44 | SIS – Senologic International Society | SIS is composed of non-profit associations, societies, scientific institutions, and groups, aiming to the promotion of knowledge in biology and medicine in human sciences, related to the breast, in order to establish an international federation, with the intention of advancing prevention, diagnosis and treatment of breast diseases, to spread senologic knowledge and to promote interaction with the community. | http://www.sisbreast.org/ |

Table 2 provides the list of projects and networks contacted by the JRC since 2011.

Stakeholders listed in italics were first approached in 2015.

Table 2. Stakeholders (projects and networks).

| No | Name | Activity | Website |
|----|--|---|--|
| 1 | <i>BenchCan</i> | <i>The general objective of BENCH-CAN is to benchmark comprehensive cancer care & yield best practice examples in a way that contributes to improving the quality of interdisciplinary patient treatment.</i> | <i>Co-funded by the Health Programme of the European Union</i> |
| 2 | CANCON – European Guide on Quality Improvement in Comprehensive Cancer Control | Purpose of this Joint Action is to address comprehensive cancer care across the member states and to set the guiding principles for its achievement. | European Commission – Joint Action |

Table 2. (cont.)

| No | Name | Activity | Website |
|----|--|--|---|
| 3 | COMET – Core Outcome Measures in Effectiveness Trials | The COMET Initiative brings together people interested in the development and application of agreed standardised sets of outcomes, known as 'core outcome sets'. These sets represent the minimum that should be measured and reported in all clinical trials of a specific condition, and are also suitable for use in a clinical audit or research other than randomised trials. | MRC Hub for Trials Methodology Research (HTMR) Network European Commission under the Seventh Framework Programme. NHS National Institute for Health Research (NIHR) |
| 4 | DECIDE – Developing and Evaluating Communication strategies to support Informed Decisions and practice based on Evidence | DECIDE is a 5-year project (running from January 2011 to 2015) whose objective is to improve the dissemination of evidence-based recommendations by building on the work of the GRADE Working Group to develop and evaluate methods that address the targeted dissemination of guidelines. | European Commission under the Seventh Framework Programme |
| 5 | ECCG – European Cooperation on Development and Implementation of Cancer Screening and Prevention Guidelines | The project aims to develop supplements to the current EU guidelines on specific topics, to maintain an EU forum for cooperation in cancer screening and guideline development and to describe the current epidemiology of breast and cervical cancer in the EU. | European Commission |
| 6 | ECHO – European Collaboration for Health Optimization | The ECHO project is an international effort to bring together the hospital databases of several European countries and make the data available via an online summary tool. | European Commission under the Seventh Framework Programme |
| 7 | ENCR – European Network of Cancer Registries | The ENCR promotes collaboration between cancer registries, defines data collection standards, provides training for cancer registry personnel and regularly disseminates information on incidence of and mortality from cancer in the European Union and Europe. | European Commission |
| 8 | EPAAC – European Partnership for Action Against Cancer Joint Action | EPAAC was a partnership that put together the efforts of different stakeholders into a joint response to prevent and control cancer. The partnership is taken forward through a new Joint Action – CANCON. | European Commission – Joint Action |
| 9 | EUnetHTA | EUnetHTA is a network of government appointed organisations (from EU Member States, EU-accession countries, plus EEA and EFTA countries) and a large number of relevant regional agencies and not-for-profit organisations that produce or contribute to health technology assessment HTA in Europe | European Commission – Joint Action |
| 10 | EURECCA – European Registration of Cancer Care | The EURECCA project aims to improve the quality of cancer care through audits (of data). The project is ongoing for colorectal cancer and at the initial stage for breast cancer. | European Society of Surgical Oncology (ESSO); European CanCer Organisation (ECCO) |

Table 2. (cont.)

| No | Name | Activity | Website |
|----|--|---|--|
| 11 | EUREGHA – European Regional and Local Health Authorities | EUREGHA is a network of 13 European Regional and Local Health Authorities focused on public health, which aim is to promote collaboration amongst regions and local authorities, more specifically regional and local health authorities in Europe, within the framework of the policies relating to public health and healthcare, as well as to establish focused collaboration with the institutions of the European Union and with the international and public organisations related to public health and healthcare throughout the world. | European Regions: Lower Austria (AT); Catalunya (ES); East of England (UK); Flanders (BE); Skåne (SE); Västra Gotaland (SE); Veneto (IT); North West of England (UK); Podlaskie (PL) |
| 12 | EUROCAN – EurocanPlatform | EUROCAN brings together 28 European cancer Institutions and organisations to work together in a unique collaboration. The centres share infrastructures and collaborate on projects to help advance cancer research and treatment. The aim of the project is to improve outcomes for cancer patients and reduce mortality. This is being achieved by focusing on three key areas of research: prevention, early detection and improved treatments. | European Commission |
| 13 | EUROCARE – Survival of cancer patients in Europe | EUROCARE is the largest collaborative research project on cancer survival in Europe. The project started in 1989 under the initiative of two research institutes, Istituto Nazionale Tumori (Milan, Italy) and Istituto Superiore di Sanità (Rome, Italy), with the participation of a large number of population-based Cancer Registries throughout Europe. The aims of the study are: to provide an updated description of cancer survival time trends and differences across European countries, to measure cancer prevalence, and to study patterns of care of cancer patients. | Italian Ministry of Health, Compagnia di San Paolo, CARIPO Foundation |
| 14 | PaSQ – Patient Safety and Quality of Care Working Group | The Commission Patient Safety and Quality of Care Working Group brings together representatives from all 27 EU countries, EFTA countries, international organisations and EU bodies. The Group assists in developing the EU patient safety and quality agenda | http://ec.europa.eu/health/patient_safety/policy/index_en.htm |

The individual stakeholders usually have one or more professional affiliations. A non-exhaustive list of public and private institutions contacted/met by the JRC (through

one or more of their representatives or employees) is reported in *Table 3*. Institutions listed in *italics* were first approached in 2015.

Table 3. *Public and private institutions indirectly contacted through one or more of their representatives*

| No | Name | Country |
|-----|---|----------------|
| 1. | <i>Abbott Diagnostics</i> | <i>Italy</i> |
| 2. | Accredia | Italy |
| 3. | Ambulatorio di omeopatia, Centro di riferimento regionale toscano, Ospedale Campo di Marte, Azienda USL 2 Lucca | Italy |
| 4. | <i>Anticancer Fund</i> | <i>Belgium</i> |
| 5. | Azienda Sanitaria Locale (ASL) di Milano | Italy |
| 6. | Breast Centre - Humanitas Cancer Centre (BCH) | Italy |
| 7. | Champalimaud Foundation | Portugal |
| 8. | CERMET | Italy |
| 9. | Centre fribourgeois de dépistage du cancer du sein | Switzerland |
| 10. | The Christie NHS Foundation Trust | United Kingdom |
| 11. | <i>Cologne University</i> | <i>Germany</i> |
| 12. | Croatian National Institute of Public Health | Croatia |
| 13. | Danish Health and Medicines Authority - Hospital Services and Emergency Management | Denmark |
| 14. | Deutsche Akkreditierungsstelle GmbH (DAkkS) | Germany |
| 15. | Direção-Geral da Saúde | Portugal |
| 16. | Emilia-Romagna Local Health Unit | Italy |
| 17. | <i>Faculty of Health Sciences – University of Copenhagen</i> | <i>Denmark</i> |
| 18. | Swiss cancer screening, Fédération suisse des programmes de dépistage du cancer | Switzerland |
| 19. | Fakultní nemocnice Olomouc | Czech Republic |
| 20. | Gesundheit Österreich GmbH | Austria |
| 21. | Gynaecological department (women's clinic) Bürgerspital | Switzerland |
| 22. | Haute Autorité de Santé | France |
| 23. | Institut Català d'Oncologia | Spain |
| 24. | Institut National du Cancer | France |
| 25. | Institute for Health Research - Lancaster University | United Kingdom |
| 26. | Institute of Oncology Ljubljana | Slovenia |
| 27. | Institute for Oncology Veneto | Italy |

Table 3. (cont.)

| No | Name | Country |
|-----|--|-----------------|
| 28. | <i>Institute of Public Health Brussels</i> | <i>Belgium</i> |
| 29. | Institute of Public Health of the Republic of Slovenia | Slovenia |
| 30. | Karolinska University Hospital | Sweden |
| 31. | Kleijnen Systematic Reviews Ltd (KSR) | United Kingdom |
| 32. | Kooperationsgemeinschaft Mammographie GbR | Germany |
| 33. | Lazio Regional Health Authority | Italy |
| 34. | London Breast Institute | United Kingdom |
| 35. | Mammografi Sverige - Unilabs AB | Sweden |
| 36. | Mario Negri Institute | Italy |
| 37. | Mass Screening Registry Finland | Finland |
| 38. | <i>Medical University of Vienna</i> | <i>Austria</i> |
| 39. | Ministero de Sanidad y Politica Social | Spain |
| 40. | Ministry for Health, the Elderly and Community Care | Malta |
| 41. | Ministry of Health | Cyprus |
| 42. | Ministry of Health | Italy |
| 43. | Ministry of Health | Poland |
| 44. | Ministry of Health of the Republic of Lithuania | Lithuania |
| 45. | Ministry of Health, Welfare and Sport | The Netherlands |
| 46. | Ministry of Social Affairs | Estonia |
| 47. | Ministère des affaires sociales et de la santé | France |
| 48. | National Cancer Control Programme | Ireland |
| 49. | National Cancer Institute Milano (Istituto Nazionale Tumori – INT) | Italy |
| 50. | National Health Service (NHS) | United Kingdom |
| 51. | <i>Norwegian Directorate of Health</i> | <i>Norway</i> |
| 52. | The Netherlands Cancer Institute | The Netherlands |
| 53. | Onkologický ústav sv. Alžbety, s.r.o. | Slovakia |
| 54. | Oslo University Hospital | Norway |

Table 3. (cont.)

| No | Name | Country |
|-----|---|-----------------------|
| 55. | Piedmont Reference Centre for Epidemiology and Cancer Prevention (CPO Piemonte) | Italy |
| 56. | Polytechnic University of Milan | Italy |
| 57. | Public Association for Healthy People | Hungary |
| 58. | Radboud University Medical Centre Nijmegen | The Netherlands |
| 59. | Riga East University Hospital | Latvia |
| 60. | The Royal Marsden, Downs Road | United Kingdom |
| 61. | Scientific Institute of Public Health | Belgium |
| 62. | <i>SP Technical Institute of Sweden</i> | <i>Sweden</i> |
| 63. | <i>Specialized Hospital for Active Treatment in Oncology</i> | <i>Bulgaria</i> |
| 64. | Syöpäjärjestöt – Cancer Society of Finland | Finland |
| 65. | Swiss Accreditation Service (SAS) | Switzerland |
| 66. | Tuscan Network for Integrative Medicine | Italy |
| 67. | Tübingen University | Germany |
| 68. | United Kingdom Accreditation Service (UKAS) | United Kingdom |
| 69. | Università di Modena e Reggio Emilia | Italy |
| 70. | University College Hospital, London | United Kingdom |
| 71. | <i>University of Groningen</i> | <i>Netherlands</i> |
| 72. | <i>University of Surrey</i> | <i>United Kingdom</i> |
| 73. | <i>University of Warwick</i> | <i>United Kingdom</i> |
| 74. | Vivantes Center for Breast Diseases | Germany |

4.2. Description of events

4.2.1. Attendance at conferences/ workshops/trainings as participants

Table 4. Attendance at conferences/workshops/trainings as participants.

| No | Date | Event | Organiser | Title | Place | Impact |
|----|---------------|------------|--|--|---------------|---|
| 1. | 20/01/2015 | Meeting | JRC | Participate to the meeting with CEN/CENELEC and EARTO on the 2015 joint meeting 'Putting Science into standards' | Brussels (BE) | The meeting was the follow-up of the previous meeting held in December 2015 where the choice of the topic for 2015 joint meeting (co-organised annually by JRC plus CEN/CENELEC plus EARTO) was discussed. JRC proposal on standardisation in the Healthcare area using the Breast Cancer Accreditation scheme as a model was taken very positively by EARTO, leaving some scepticism in CEN/CENELEC. This second meeting succeeded in convincing them that the event can offer a platform for open discussion among the main stakeholders (from industry to research, from health technology assessment to patients, from healthcare Institutions to insurances) to receive a feed-back on standardisation needs and formats in this area. |
| 2. | 29-30/04/2015 | Workshop | Association of European Cancer Leagues (ECL) | ECL PSWG (Patient Support Working Group) meeting | Limassol (CY) | The meeting focused on different approaches in the Member States towards the CAM (Complementary alternative Medicine) used in cancer patients. The most developed in the integration of the CAM seems to be Toscana Region, where CAM therapies are included in the regional health legislation. |
| 3. | 07-9/05/2015 | Conference | European Society for Medical Oncology | IMPAKT Breast Cancer Conference | Brussels (BE) | The main topic of the conference was improving care and knowledge through translational research in breast cancer. There were approximately 500 registrations to this conference which apparently is the only one in the field of translational research in breast cancer. The programme focused on the clinical significance of genomic patterns and mutations, the mutational evolution in breast cancer, cellular origin of breast cancer and translational research in the context of clinical trials in early breast cancer. The need to standardise PET images was brought up as well as the need for cross talk between radiologists and molecular oncologists in order to show the clinical usefulness of imaging. |

Table 4. (cont.)

| No | Date | Event | Organiser | Title | Place | Impact |
|----|---------------|------------|---|--|---------------|---|
| 4. | 7-8/05/2015 | Workshop | German Cancer Society, in cooperation with UICC | 2st European Round Table Meeting to Discuss Quality of Cancer Care | Berlin (DE) | Several issues that may impact the <i>European QA Scheme</i> were discussed, such as continuity and coordination of care, patient's involvement and use of data and cancer registries. The conclusions of the workshop are published in Ortman O, Torode J and Helbig U. Improving structural development in oncology: transformation of theoretical health care standards and knowledge into a practical approach. <i>J Cancer Res Clin Oncol</i> 2015; DOI 10.1007/s00432-015-2052-9 |
| 5. | 22-24/06/2015 | Conference | Organisation of European Cancer Institutes (OECI) | OECI 2015 Oncology Days | Porto (PT) | The qualitative and quantitative tools developed within the BenchCan project and the experience within the benchmarking process during the pilot sites visits were presented. The feedback regarding the patients' needs was also highlighted by a representative of ECPC. OECI core activities were also covered. The process of OECI for accreditation and designation was discussed. The practical issues raised by the pilot centres for the BenchCan project might be useful also for the QA scheme (e.g. creation of a glossary of terms – different countries interpreted in different ways some indicators). |
| 6. | 3-4/09/2015 – | Workshop | CERES – Cologne center for ethics, rights, economics, and social sciences of health | IMPAKT Breast Cancer Conference | Brussels (BE) | The role, the scope and the goals of the RiskAP project were discussed. The main aim will be to define the existence and needs of evidence for genetic testing, also in the context of stratified breast cancer screening, and preventive treatment. The working group will meet other four times for preparing a position paper. The last meeting will be hosted by the German Federal Ministry of Health. One of the draft Work packages proposed would include management of data and the members of the working group proposed to have a dialogue with cancer registries. |
| 7. | 21/09/2015 | Workshop | Institute for Prospective Technological Studies (IPTS)-JRC Sevilla | Presentation of the MAFEIP tool | Brussels (BE) | The Healthcare Quality Team may consider using the MAFEIP tool to evaluate the impact of the European Commission Initiative on Breast Cancer. |

Table 4. (cont.)

| No | Date | Event | Organiser | Title | Place | Impact |
|----|---------------|----------|--|--|-------------|---|
| 8. | 25-29/09/2015 | Congress | European Society for Medical Oncology (ESMO) | European Cancer Congress 2015 (ECC 2015) | Vienna (AT) | <p>The ECC 2015 combined the efforts of the most important European oncology professionals with the aim of improving the prevention, diagnosis, treatment and care of cancer patients.</p> <p>Particularly sessions focusing on the multidisciplinary approach in cancer treatment and care, and implementation of clinical practice guidelines will have impact on the ECIBC future work on QA scheme and guidelines.</p> <p>Discussions to be continued on the inclusion of the rare breast cancer in the European Reference Network on rare cancers.</p> <p>The presence of ECIBC in the future breast and general oncology conferences is important both for the visibility of the project and for enhancing collaboration with different organizations and stakeholders.</p> |

4.2.2. Attendance at conferences/ workshops/trainings as presenters

Table 5 presents the list of events held in 2015 where the JRC gave presentations related to the ECIBC.

Table 5. Attendance at conferences/workshops/trainings as presenters.

| No | Date | Event | Organiser | Title | Impact |
|----|---------------|--|--|--|---|
| 1. | 25-29/09/2015 | Congress | European Society for Medical Oncology (ESMO) | European Cancer Congress 2015 (ECC 2015) | EU voluntary accreditation scheme for breast cancer services and revision/integration of the 4th edition of the European guidelines |
| 2. | 1-4/06/2015 | International Cancer Screening Network | International Cancer Screening Network (ICSN) triennial conference | Rotterdam (NL) | Presence and characteristics of breast cancer screening programmes in 28 European countries: results from two international surveys |
| 3. | 19/06/2015 | Senonetwork Eusoma Conferenza Stato – Regioni for Breast Units Italian Regulation implementation | ‘Breast Unit: il 2016 è alle porte. 5 th Pavia Update on Breast Cancer’ | Milano (IT) | The European Commission Initiative on Breast Cancer: a voluntary quality assurance scheme for Breast Cancer Services |

Table 5. (cont.)

| No | Date | Event | Organiser | Title | Impact |
|----|--------------------|--|---|----------------|---|
| 4. | 2-3/10/2015 | EUSOBI | EUSOBI Annual Scientific Meeting 2015 | London (UK) | The New European Guidelines for breast cancer screening and diagnosis |
| 5. | 08-09/10/2015 | DG Health and Food Safety | 2 nd conference on European Reference Networks | Lisbon (PT) | JRC registries project and potential interaction with ERNs |
| 6. | 15-17 October 2015 | European Public Health Association | 8 th European Public Health Conference | Milan (IT) | Implementation and equity trends in twenty-five years of European mammography screening programmes. Requirements for breast cancer data collection: systematic review of European funded projects |
| 7. | 12-13/11/2015 | Ministry of Education, Science and Sport, Republic of Slovenia | Joint Research Centre & Slovenia Thematic event to foster cooperation | Ljubljana (SI) | The European Commission Initiative on Breast Cancer |
| 8. | 20/11/2015 Lecture | The Hellenic School of Senology Greece ECIBC National Contact – GDG member | Lecture on JRC work on Breast Cancer | Athens (GR) | The European Commission Initiative on Breast Cancer |

4.2.3. Meetings with EC institutions

During 2015, the HQ team participated in the *EU Patient Safety and Quality of Care Expert Group* (the former *Patient Safety and Quality of Care Working Group*) meetings coordinated by DG SANTE on a regular basis and in the *Accreditation Steering Group* organised by the Directorate-General for Internal Market, Industry, Entrepreneurship and SMEs. The JRC also had meetings with DG SANTE, DG GROW, DG RTD and EMA. These events are not described as they do not fall under the scope of this report. Also JRC attended the meetings of the Commission Expert Group on Cancer Control.

4.2.4. Attendance at events related to the CANCON joint action

In 2015, the JRC participated in several events organised within the framework of the CANCON joint action. A presentation entitled *Potential areas of collaboration of the Joint Research Centre with CANCON WP9* was given at the CANCON WP9 (Cancer Screening) kick-off meeting.

Table 6. JRC participation at CANCON events.

| No | Period | Meeting | Location |
|----|---------------|---|---------------|
| 1. | 12-13/02/2015 | Participation of the JRC at the CanCon WP9 (Screening) Coordination meeting | Lyon (FR) |
| 2. | 12-13/05/2015 | Participation of the JRC at the CANCON Stakeholder Forum, CANCON WP2 meeting and CANCON WP5 Cancer Survivorship and Policy Dialog with EP MAC | Brussels (BE) |
| 3. | 17-18/09/2015 | Participation of the JRC at the CanCon WP9 (Screening) Breast Cancer meeting with the presentation 'Current status of breast cancer screening implementation in Europe' | Zagreb (HR) |

4.2.5. Bilateral meetings with organisations or individual experts

In 2015, nine bilateral meetings including videoconferences, teleconferences and on-site meetings were organised with some of the stakeholders included in *Tables 1 to 3*.

4.3. ECIBC updates

Like in the previous years, ECIBC preparatory activities included stakeholders meetings, participation in external events, literature searches, outsourcing services for ECIBC tasks (literature review), and publication of the reports:

Review and analysis of external quality assessment of breast cancer services in Europe—Supporting information from the development of a European Quality Assurance scheme for Breast Cancer Services.

Report of a survey on accreditation and conformity assessment in the field of breast cancer in

Europe—Supporting information from the national accreditation bodies for the European Commission initiative on breast cancer.

As mentioned in the results section, both the Guidelines Development Group and Quality Assurance Scheme Development Group (QASDG) were nominated in July 2015 and the kick-off meetings were held in September.

Another important event was the conference entitled 'Putting Science into Standards: Evidence-based quality assurance—an example for breast cancer' organised by JRC together with the European Association of Research and Technology Organisations (EARTO), the European Committee for Standardization (CEN), the European Committee for Electrotechnical Standardization (CENELEC), and the Directorate-General for Internal Market, Industry, Entrepreneurship and SMEs.

During 2015 the feasibility study and the deployment for the ECIBC web hub were performed.

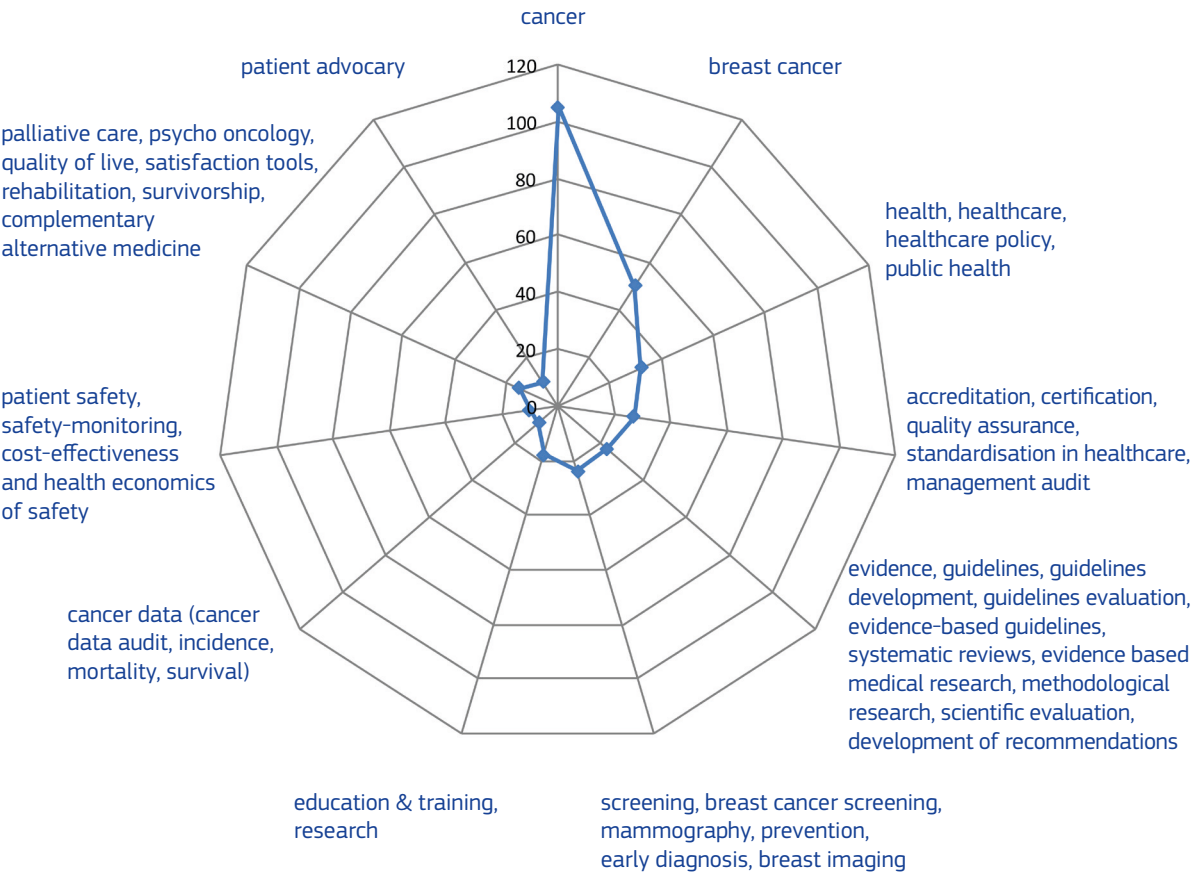
The organisation of the Plenary of the ECIBC ‘Improving breast cancer screening, diagnosis and care in Europe and the launch of the ECIBC web hub will contribute also to the dissemination of the ECIBC.

4.4. Meetings analysis

The networking activities since the beginning of the ECIBC are analysed. The meth-

ods used to perform the analysis have already been described in the report *European Commission Initiative on Breast Cancer– ECIBC: organisation of project guiding and support meetings– Meetings 2014*. ECIBC-defined keywords were assigned for each meeting. The keywords were grouped into clusters. A diagram showing the results can be seen in *Figure 1*. In the diagram, the numbers reflect the frequency of the keywords allocated to the meetings and not the total number of meetings. Based on these numbers, decisions concerning networking and collaboration priorities can be made.

Figure 1. Synthetic overview on area of interest for the ECIBC.



Conclusions

2015 was an intensive year for ECIBC. The project gained visibility. The networking activities included participation in external events and meetings with stakeholders from the area of breast cancer, healthcare, quality assurance, methodological research, clinical

trials, cancer research, complementary and alternative medicine, screening.

JRC will continue to present updates regarding ECIBC during future meetings and to meet stakeholders.

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